FIRST STEPS AND BEYOND:

Incorporating Shared Decision Making in Massachusetts Mental Health Services

Report and Recommendations from the 2009 Summit

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While the construct of compliance can serve to silence and conceal the complex treatment decision-making processes of people with long-term disorders, shared decision-making is predicated on breaking silence and enhancing dialogue between practitioners and clients.

Pat Deegan[1],
Pat Deegan, Phd & Associates, LLC,

<u>A note from Dr. Foti</u>… "As the State Medical Director of the MA Department of Mental Health, I represent our practitioners and practices. Seeing patients as true partners and expert in their history and health can be challenging. Simply put, we were not trained that way. However, we have the motivation and competence to change – what is needed are effective pilot programs, demonstrations, and system wide trainings that model shared decision making and effectively address providers' concerns."

<u>A note on language from Jonathan Delman</u>… "There is no universal terminology to describe the people who have receive(d) psychiatric services even among those of us with lived experience of mental illness and/or distress. When discussing the provider-person relationship, I tend to use the term "client" as my best shorthand. This is because I am an attorney, and I was taught that I have an ethical duty to zealously represent my clients according to their wishes."

[1] Deegan, P. E. (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. *Psychiatric Rehabilitation Journal, 31,* 62–69., 64.

Executive Summary

- On June 25th 2009, Consumer Quality Initiatives (CQI) and the Massachusetts Department of Mental Health (DMH) held a policy summit in Waltham Massachusetts entitled: "*Shared Decision Making in Mental Health Services: First Steps towards a Statewide Approach*." Over 100 members of various stakeholder groups attended, watched the plenary presentations, and participated in the afternoon break-out groups.
- "Shared decision-making" has been defined as "an interactive process in which physicians [providers] and patients [clients] simultaneously participate in all phases of the decision-making process and together negotiate a treatment to implement". It is now considered a cornerstone of recovery-oriented mental health services.
- Recent studies show that a large majority of people with mental illnesses want to be active participants in treatment decision making and are capable of doing so.
- While summit participants agreed that SDM is a desired norm of mental health service provision, it's not commonly seen in practice, and in fact there are significant barriers to achieving SDM.
- Participants identified several barriers to achieving SDM in MA mental health, including:
    - SDM challenges the current norms and attitudes of provider agency operations and staff practices, requiring new policies and trainings to overcome staff resistance.
    - Providers often assume that a client wants to maintain a current level of participation in decision making, even though the client may want more.
    - Clients will have various perspectives on the notion of participation in treatment decision making, often arising from their cultural background.
    - Many people, regardless of their mental status, are not comfortable making choices, particularly when there is little support and information.
    - We are still in the process of identifying the most effective and feasible client decision support tools.
    - Peer specialists have the potential to serve as effective decision coaches, but we are only beginning to learn how to successfully include peers specialists as part of treatment teams.
- Based on these findings, the plenary presentations, and the reports of the breakout groups, we recommend the following first steps for establishing SDM in Massachusetts:
    - Call to Action: Policy Leaders Send a Clear Message that SDM is Critical to High Quality Care
    - Establish a Multi-Stakeholder SDM Task Force, and Seek Funding for It
    - Create a SDM Website for Massachusetts
    - Conduct a Series of Stakeholder Needs Assessments
    - Develop a Workforce Training Strategy
    - Formalize the Role of the Peer Specialist in Providing Decision Support
    - Address Risk/Liability Concerns, and Propose Legislation
    - Address Racial and Ethnic Factors in SDM

Introduction

Over the last decade, the public mental health system in the United States has begun to shift from a traditional, medical model of care, toward the provision of "recovery-oriented" services. This movement has been driven by consumers and other stakeholders who observed that the traditional service system has focused primarily on symptom reduction and client stability, thereby failing to foster a sense of encouragement and hope among consumers.[1] The traditional approach has not included consumers and family members as equal partners in the treatment process. [2]

The recovery-oriented approach to mental health care goes beyond symptom management by supporting clients to "live, work, learn, and participate fully in their communities."[3] Recovery-oriented practitioners identify and promote an individual's strengths. They respect a person's right to make his or her own decisions, and they emphasize relapse prevention and crisis planning.[4] The recovery model of care embraces the "dignity of risk," where the possibility of success outweighs the fear of failure within a system that supports and values every person.[5] The recovery movement gained momentum in 2003 with the establishment of the President's New Freedom Commission on Mental Health, and with publication of the Commission's report, *Achieving the Promise: Transforming Mental Health Care in America.*[6]

Shared Decision Making (SDM) has been defined as "an interactive process in which physicians [providers] and patients [clients] simultaneously participate in all phases of the decision-making process and together negotiate a treatment to implement."[7] As stated in the President's New Freedom Commission report, SDM with regard to treatment and services is a foundation of the recovery-oriented approach.[8]

On June 25th 2009, Consumer Quality Initiatives ("CQI") and the Massachusetts Department of Mental Health ("DMH") held a policy summit in Waltham, Massachusetts entitled, "*Shared Decision Making in Mental Health Services: First Steps Towards a Statewide Approach."* Over one hundred invited guests gathered to learn about the principles of SDM, and to discuss the opportunities and challenges of its implementation in Massachusetts. Attendees included mental health providers, consumers, family members, researchers, policy leaders and other government officials. Financial support for the summit was provided by the Robert Wood Johnson Foundation's Community Health Leaders program.[9]

This White Paper reviews early efforts to strengthen the role of the consumer in treatment decision making; it describes SDM and its benefits and challenges; and it summarizes the proceedings of the SDM summit. Finally, it presents a series of recommended first steps for incorporating SDM in Massachusetts' mental health services. The White Paper and its recommendations draw extensively from the presentations and discussions that took place at last year's summit. The authors call for bold changes and improvements to our mental health delivery system.

Background

- Early Endeavors at Consumer Involvement in Mental Health Decisions in Massachusetts
- What is Shared Decision Making?
- Benefits of SDM
- Barriers to SDM
- Overcoming Barriers with Decision Supports
- A Visual Summary of SDM

Early Endeavors at Consumer Involvement in Mental Health Decisions in Massachusetts

Consumers of mental health services in Massachusetts have, for many years, voiced concerns about the lack of information they receive from their psychiatrists regarding their general treatment, and their medications in particular. In 1987, a group current and former mental health consumers came together to form a grassroots advocacy organization called Massachusetts People/Patients Organized for Wellness, Empowerment, and Rights ("M-POWER") to document and address their common concerns.

Soon after its inception, M-POWER was flooded with stories of consumers who had received little or no information from their psychiatrists about treatment options. Many people had experienced serious medication side effects from prescribed treatments, and a significant number felt coerced into taking medications. Psychotropic medications may produce harmful and uncomfortable side effects, which over time can have a substantial impact on a person's quality of life.

In 1991, members of the Boston Chapter of M-POWER studied the legal and ethical requirements of Informed Consent to Treatment ("Informed Consent"). Informed Consent requires that prior to prescribing a treatment, the mental health provider shares information with the client on available treatments and the corresponding benefits and risks of each. The client then uses that information to make a treatment decision for him or herself.

M-POWER members organized a campaign to establish Informed Consent as clear and deliberate policy of DMH, the state mental health authority. [10] In 1996, after a period of negotiations, DMH reached consensus with M-POWER and implemented a policy of Informed Consent. The policy required providers to fully disclose and discuss treatment and/or medication options with a client, and it required that the client assert consent by signing a written form that outlined the agreed-upon treatment. The form, which was signed in triplicate, was then kept on file by the psychiatrist, the client, and within the client's medical record.

Although the Informed Consent policy was well thought out, its implementation was patchy at best. In early 2000, M-POWER members joined the DMH Medical Director to meet with a

statewide group of DMH psychiatrists; members learned that many psychiatrists continued to believe that sharing side effect information with patients served little or no value. Throughout the 2000's, consumer evaluative studies in MA conducted by CQI continued to show patient dissatisfaction with the information psychiatrists provided to them about medications.[11]

Toward the late 2000's, DMH and its partners began to take steps to promote SDM between psychiatrists and clients. In 2008, the Massachusetts Behavioral Health Partnership ("MBHP") selected Pat Deegan's *CommonGround* clinical decision support model[12] for use with clients seeing psychiatrists at three outpatient clinics in Massachusetts. With the *CommonGround* model, the waiting areas of the three clinics were transformed into Decision Support Centers that featured peer specialists and "a user-friendly Internet-based software program with which clients could create a one-page, computer-generated report for use in the medication consultation."[13]

In 2009**,** DMH procured a new treatment model called Community Based Flexible Supports ("CBFS") for its contracted outpatient treatment services. Services provided under the CBFS activity code were required to be person-centered, "responsive to the preferences and needs of individuals and their families and focused on rehabilitation and recovery."[14] Although the CBFS model has represented a welcome shift toward recovery-oriented services, it does not include a defined methodology or process for provider/consumer communications that represents person-centered planning.

What is Shared Decision Making?

SDM is defined as "an interactive process in which physicians [providers] and patients [clients] simultaneously participate in all phases of the decision-making process and together negotiate a treatment to implement."[15] Essential components of SDM are: establishing a context in which clients' views about treatment options are valued and deemed necessary, transferring technical information, making sure clients understand this information, helping clients base their preference on the best evidence coupled with their own values and knowledge about themselves; eliciting clients' preferences, sharing treatment recommendations, and making explicit the component of uncertainty in the clinical decision-making process.[16]

SDM begins with the premise that the client chooses what role he/she prefers in the decision making process and the provider seeks to understand and respect the client's choice throughout their partnership. SDM recognizes that both providers and clients have important knowledge to contribute to the decision making process.[17] Providers are seen as having the most accurate and current information regarding the nature of the client's health condition, its course, and the treatment options.[18] Clients are seen as experts on their health history, values, treatment goals, and treatment preferences.[19] Thus, it is expected that the SDM process will be simultaneously informed by the best medical evidence available to the provider, and weighted according to the specific characteristics and values of the patient.[20]

SDM is not informed consent. Informed consent describes a unilateral decision made by a client who has been provided all relevant treatment information. SDM is a concurrent, fluid exchange of information between client and provider (patient and physician) in a mutual attempt to reach a consensus treatment decision(s).

Benefits of SDM

Recent studies have found that the majority of people with mental illnesses want to participate in treatment decision-making and are able to do so.[21] [22](CQI's own studies have shown that most mental health clients want to participate in making treatment decisions with their psychiatrists.) In addition, research demonstrates that when decisions reflect patient preferences, a variety of benefits result. These benefits may include increased service satisfaction, improved treatment adherence, and decreased symptom burden.[23], [24], [25] As clients become more active in decisions about their treatment, they also share more responsibility for the consequences of those decisions.[26] Active involvement in treatment decision making may lead to improved self-esteem and self-management skills.

The potential benefits resulting from SDM are particularly promising in mental health care, where most treatment options are "preference-sensitive." Effective care is where evidence of benefit clearly outweighs harm: clients should always receive this type of care, where indicated. Preference-sensitive care describes a situation where the evidence for the superiority of one treatment over another is either not available or does not allow differentiation; in this situation, there are two or more valid approaches, and the best choice depends on how individuals value the risks, benefits and side effects of treatments.[27]

Decisions regarding the use of certain psychiatric medications are preference-sensitive. For example, all antidepressants and all but one antipsychotic medication have equal efficacy when used in a population. The major difference between these medicines then becomes the varying side effects that each medication may cause for an individual.[28] Helping clients consider their options in the context of their own lifestyles is paramount in the decision making process. For example, a consumer who works in an intellectually demanding job may prefer a medication that is not sedative, while an individual who is focused on dating and sports might prefer a medication that does not cause weight gain and obesity.[29]

Barriers to SDM

Although many benefits accrue from SDM, many people with serious mental illness ("SMI") who want to be active participants in treatment decision making are not involved in the process.[30], [31] The mental health client-provider relationship carries with it particular encumbrances that have resulted in barriers to collaborative and effective decision making.[32] Some barriers that can stand in the way of SDM include the following:

- Providers sometimes assume that a client is not interested in sharing in the decision making process, when some probing and support may demonstrate otherwise.
- Providers may question the validity of a client's perspective; a provider may consider the client injudicious as a consequence of his or her illness.[33]
- Provider's and client's views of stability and risk may differ. As a result, clients and providers may have completely different expectations from their meetings.

- Psychiatric practice has become largely psychopharmacological evaluation and treatment monitoring. These changes have led to severe reductions in the time spent providing services directly, with visits with psychiatrists to discuss medications generally lasting in the range of 10-20 minutes[34]. Time restrictions present challenges to both psychiatrists and clients, who face the pressure of trying to fully process, weigh, and discuss multiple options within about fifteen minutes
- Many clients are reluctant to share with their providers an honest assessment of their care.[35]
- The SDM model assumes that both parties are able to comprehend the requisite information to make the best treatment decisions, but that is often not the case. Many people with mental illnesses are poorly educated, lack appropriate resources, and/or have difficulty with concentration.

Overcoming Barriers with Decision Supports

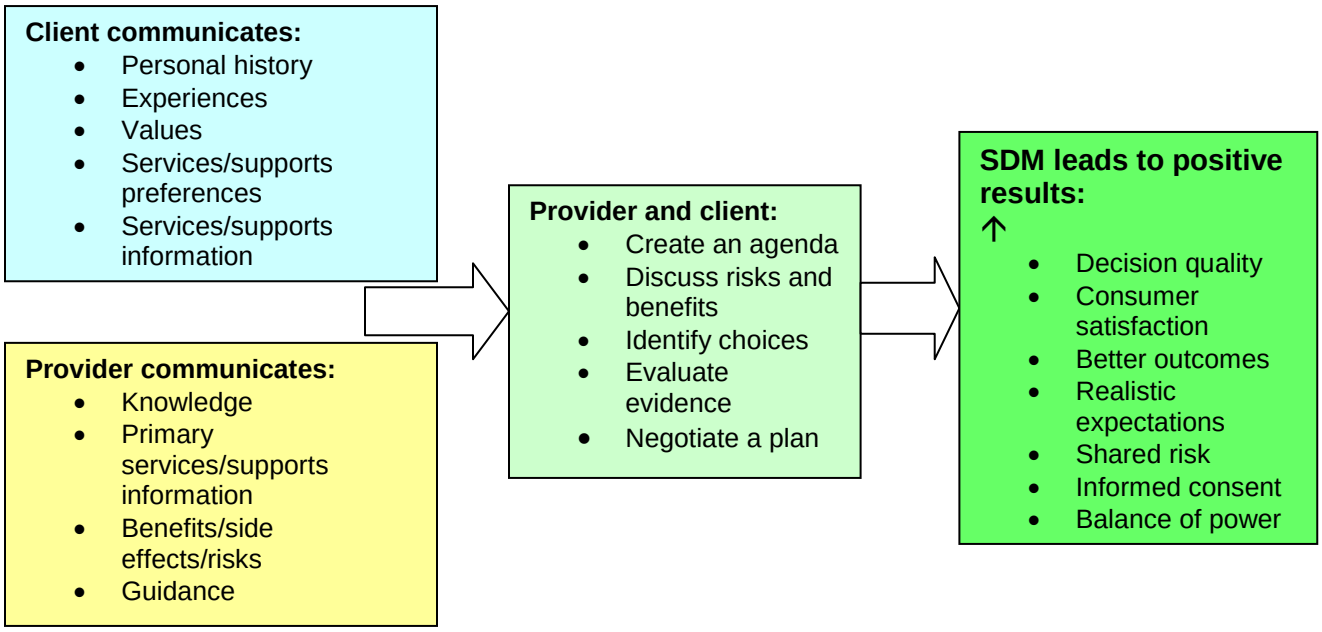
Some barriers to SDM can be overcome with appropriate supports. It is important for clients to have supports to help them obtain all relevant treatment information, and to help them clarify their values regarding the potential benefits, risks and side effects of the treatment options. With effective supports, many clients can actively participate in making treatment decisions with providers.

One common type of decision support is the client "decision aid," which provides concrete information about a health condition and the potential outcomes of different treatment options, and helps the client to clarify his or her personal values. There has been a recent push to develop decision aids for people with SMI, but few decision aids have been evaluated for their effectiveness.[36] The Substance Abuse and Mental Health Services Administration ("SAMHSA") has a Consumer/Survivor Initiative Website devoted to SDM, including SDM Webinars, communication tools, tips and briefs for mental health clients and providers. SAMHSA is also supporting the development of an "interactive, web-based decision aid focusing on a decision relevant to antipsychotic medications."[37] Like all decision supports, decision aids are designed to complement, not replace, the advice of providers.

Other types of decision supports include client self-advocacy trainings, question-formulation preparation,[38] and assistance with the development of printed provider meeting agendas[39]. Decision supports can be delivered via printed materials; via in-person or web-based presentations; or through interactive experiences such as audio-guided workbooks, electronic shared spaces such as Google groups, and personal coaching or mentoring.[40] Decision supports that are interactive not only have great potential to engage clients, but also to empower them to manage and take control of their illness.

A Visual Summary of SDM

The process of SDM can be summarized in a visual way as follows:



The Shared Decision Making Summit, June 2009

- **Overview of the Summit**
- **Key Findings from the Summit**

Overview of the Summit

The policy summit held by CQI and DMH, "*Shared Decision Making in Mental Health Services: First Steps towards a Statewide Approach,"* was an invigorating day of sharing among a diverse group of over 100 mental health professionals, policy leaders, consumers and family members. Held on June 25th, 2009 in Waltham, Massachusetts, the Summit was an opportunity for invited guests to learn about SDM and to discuss the opportunities and challenges of its implementation in Massachusetts. (Financial support for the summit was provided by the Robert Wood Johnson Foundation's Community Health Leaders program[41].

The day began with introductions by Jonathan Delman, CQI's Executive Director and Robert Wood Johnson Community Health Leader awardee, and Dr. Mary Ellen Foti, DMH Deputy Commissioner of Clinical and Professional Services. DMH Commissioner Barbara Leadholm and State Representative Jason Lewis (D-Winchester) followed with words of inspiration and deep interest.

Plenary presentations were delivered by the leading innovators of SDM in mental health treatment: Dr. Robert Drake, Professor of Psychiatry, Community, and Family Medicine at

Dartmouth Medical School, and Pat Deegan, PhD, renowned consumer/survivor, leader and designer of the *CommonGround* SDM software.

A consumer panel entitled "Consumer Perspective" and a provider panel entitled "The Provider's Challenge" followed the plenary presentations. The panelists offered their unique perspectives on the decision making process between clients and providers, and they emphasized the potential that exists for greater collaboration in these treatment decisions.

Following a networking lunch, summit participants broke into small groups to engage in facilitated, interactive dialogues about how to embed SDM in mental health policy and practice. Each group prepared and presented recommendations to the larger group based on their discussion of a specific topic. Seven working groups, each comprised of between six and ten participants, offered recommendations on a total of five topics. These topics were:

- The risks and rewards of SDM;
- Creating clinical guidelines and policy to support SDM (2 groups)
- Supports and training for clients to engage in SDM;
- Supports and training for service providers to engage in SDM with clients;
- The role of peer support in SDM (2 groups).

In depth discussion summaries for these five topics may be viewed at http://www.cqi-mass.org/shared.aspx.

Key Findings

The Summit provided a framework to obtain important input from a variety of stakeholders on implementing SDM in Massachusetts. Summit participants agreed that although SDM may be a desired norm of mental health service provision, significant barriers exist with regard to its implementation. It is clear that we are in the early stages of embracing the changes necessary to be a system characterized by SDM.

We also learned that many providers have concerns about the adoption of SDM, and that many consumers lack the resources and support to actively participate in SDM.

Some of the key barriers identified include the following:

- SDM challenges the current norms and attitudes of provider agency operations and staff practices, requiring new kinds of provider trainings. Significant staff resistance to implementing SDM is likely.
- SDM is a new concept for many in provider leadership, so extra efforts will be needed to convince administrators and clinicians to change the nature of their policies and practices.
- For providers, there is insufficient access to clinically useful scientific knowledge and facilitated communication.[42]
- Clients will have various perspectives on the notion of participation in treatment decision making, often as a consequence of their cultural background.

- Many people, regardless of their mental status, are not comfortable making choices, particularly with little support and information.
- We are still in the process of identifying the most effective and feasible client decision support tools.
- Peer specialists have the potential to serve as effective decision coaches, but we are only beginning to learn how to successfully include peers specialists as part of treatment teams.

It is clear that adoption of SDM in the Massachusetts public mental health service delivery system will require more than the development of written policy statements. Creating and sustaining a change in practice and culture always requires strong leadership, and a structured organized approach. Disseminating the best information and resources to support SDM, and monitoring and evaluating their effectiveness, is vital to the success of such an initiative.

Moving Forward: Recommendations for Incorporating SDM in Massachusetts Mental Health Services

The recommendations listed below, and described in further detail on the following pages, are based primarily on the working group discussions and recommendations from last year's SDM summit. They are also supported by the relevant literature on SDM and on organizational change. Recommended first steps to incorporate SDM in Massachusetts' mental health services include the following:

1. **Call to Action: Policy Leaders Send a Clear Message that SDM is Critical to High Quality Care**
2. **Establish a Multi-Stakeholder SDM Task Force, and Seek Funding for It**
3. **Create a SDM Website for Massachusetts**
4. **Conduct a Series of Stakeholder Needs Assessments**
5. **Develop a Workforce Training Strategy**
6. **Formalize the Role of the Peer Specialist in Providing Decision Support**
7. **Address Risk/Liability Concerns, and Propose Legislation**
8. **Address Racial and Ethnic Factors in SDM**

1. Call to Action: Policy Leaders Send a Clear Message that SDM is Critical to High Quality Care

When a significant systemic change is necessary, policy leaders such as the DMH Commissioner and State Medical Director must express their personal commitment to that change. Leadership should establish this commitment by sending clear and consistent messages to stakeholders that SDM is critical to high quality mental health care. In addition, leadership should formally announce that SDM implementation is a major objective and highlight the existing projects that already fit within this objective.

An initial letter should explain why DMH is pursuing a SDM initiative; it should outline short term and long term expectations for the initiative; and it should describe what is expected of

stakeholders. It is also important to acknowledge the challenges posed by the current financial climate, and the challenges that present with any large scale transformation. In its initiation and implementation of SDM across the service delivery system, DMH should embrace organizational change principles such as modeling, observational learning, and reminding staff that they have the competence to achieve this goal.

2. Establish a Multi-Stakeholder SDM Task Force, and Seek Funding for It

Organizing the SDM initiative will require the time and resources of many people. The authors have personally agreed to commit their time and resources to the SDM initiative. In addition, DMH, through its Research Centers of Excellence and other avenues, should seek grant funding to support the SDM Initiative.

A SDM task force should be established and include policy leaders, early practitioners of SDM, mental health consumer and family members, and other stakeholder representatives. Several members could be drawn directly from the group of summit attendees. The authors will also identify key opinion leaders - highly respected stakeholders who have influence over their peers' opinions and actions - to seek their buy-in and support for developing the task force. Leadership should educate and discuss with the opinion leaders the SDM initiative, either through formal meetings and presentations, or through more informal communications.

The task force should meet regularly to share information on important SDM developments, problems and opportunities; to develop mutually informed SDM strategies; and to support the implementation of SDM throughout the system. Task force discussions and deliberations should include not only face to face meetings, but also teleconferences, webinars, discussions on networking websites, and/or other online community building tools.

A successful model for this task force approach is the Transformation Committee ("TRANSCOM"), whose goal has been to develop and implement mental health peer services in Massachusetts. TRANSCOM's membership has included representatives from several consumer lead organizations, the Association for Behavioral Health ("ABH"), state agencies, and managed care organizations. TRANSCOM first developed mission and vision statements and work plans, and it later became a subcommittee of the Mental Health State Planning Council. Ultimately, TRANSCOM assisted the consumer-run Transformation Center in developing the Massachusetts certified peer specialist training. Members helped DMH and MBHP codify the role of the certified peer specialist in various services, and they nurtured the development of the peer-lead, DMH-funded "Recovery Learning Community" model.

3. Create a SDM Website for Massachusetts

A website established specifically for Massachusetts mental health SDM activities on the DMH internet site as well as CQI's website. CQI's website, www.cqi-mass.org, currently includes a summary of last year's SDM summit; this section could be enhanced to provide key SDM information and updates to Massachusetts stakeholders, including:

- this White Paper and the results of other related proceedings;
- a summary of SDM-related research and demonstration projects that have been taking place in Massachusetts, including the use of *CommonGround;*
- a SDM bibliography and literature reviews;
- links to other key websites, including SAMHSA's SDM website (http://mentalhealth.samhsa.gov/consumersurvivor/shared.asp).

4. Conduct a Series of Stakeholder Needs Assessments and Demonstration Projects

Participants at the SDM summit agreed that a series of in-depth needs assessments should be conducted in preparation for the establishment of SDM in Massachusetts. A needs assessment is a systematic exploration of the way things are (opinions, attitudes, practices, etc) and the way they should be. The results of a needs assessment can lay the foundation for developing the initiative's goals and objectives.

At a minimum, needs assessments of two target audiences should be conducted: providers and clients. The general goals of these needs assessments should include the following:

- To identify existing supports and barriers to SDM for each group;
- To identify methods for minimizing barriers and maximizing supports for SDM;
- To maximize the opportunity to create a proposal for change that is as tailored as possible to the specific needs of each group.

a. Needs Assessment and Demonstration Projects Targeting Mental Health Providers

Summit participants offered the following specific recommendations with regard to a needs assessment targeting mental health providers:

- The provider needs assessment should review the current practices and capacity of agencies to provide administrative oversight of their services through policies, incentives, and accountability.
- The assessment should evaluate the capacity of supervisors to provide a consistent message regarding SDM.
- Because the goal and challenge is to transform the overall culture of providers, it will be important to assess the existing level of staff knowledge, attitudes and skills around SDM implementation and use.
- Academic detailing is the face-to-face education of prescribers, designed to improve their prescription practices. Academic detailing has shown demonstrated success in changing prescribing patterns. The provider needs assessment should evaluate the feasibility of implementing a program of academic detailing for psychiatrists to promote SDM.

In order to facilitate the adoption of SDM among providers, several issues must be addressed. Providers have reported that their three most often reported facilitators to using SDM have been: provider motivation, positive impact on the clinical process, and positive impact on patient outcomes.[43] Facilitating continuing medical education for current physicians as well as introducing SDM into the medical school curriculum for future physicians will be

important. However, we know from the organizational change literature that education and training are necessary, but not sufficient components of changing a system.[44] Therefore, implementation should include promoting a culture of recovery and inclusion, a recognition of the value that prescribers bring to the process of SDM, as well as developing DMH as a learning organization rooted in the extensive use of data and ongoing change, improvement, and innovation.[45]

Specific recommendations include promoting pilot projects such as the polypharmacy reduction initiative, to show feasibility and positive impact on the clinical process as well as demonstrate that SDM does not have to be restricted to certain select clients or to certain psychosocial variables. Demonstration and expansion of successful projects like CommonGround can show that decision support tools facilitate the provider-client conversation without taking up extra time.

b. Needs Assessment Targeting Mental Health Clients

Summit participants offered the following specific recommendations with regard to a needs assessment targeting mental health clients:

- The client needs assessment should evaluate the extent to which clients wish to participate in services/treatment decision making, and the ways in which they wish to be involved.
- Results of the assessment should be sorted to determine how client preferences may vary relative to the following:
    - by category of client (e.g. race/ethnicity, age, gender)
    - by the type of decision (e.g. medication, vocational support, therapist)
- The assessment should evaluate which kinds of general and specific decision supports are best for helping people with mental illness to identify their needs and preferences regarding various treatment options. The assessment should seek to determine which decision supports are easiest and most likely to be utilized by clients, and which ones will help clients make high quality decisions.
- The assessment should seek to understand how decision supports can best be utilized to remove some of the anxiety people often feel when faced with difficult decisions.
- The assessment should help to determine the role certified peer specialists can play in providing decision support (see #6 below).

Stakeholders should leverage existing resources and work with interested researchers to conduct these needs assessments.

5. Develop a Workforce Training Strategy

After appropriate needs assessments are conducted and analyzed, a comprehensive workforce training strategy should be developed to prepare providers for the implementation of SDM. As described above, the provider needs assessment should assess workers' knowledge, skills and attitudes regarding SDM, along with their willingness to change their practice patterns. Training in the practice of SDM should be tailored to specific providers according to their level of access

to information about service options, the experiences they have had working with consumers, and the team culture within which they work.

Different types of providers (e.g. psychiatrists, peer specialists, social workers) working in different types of environments (e.g. clinics, clubhouses, Programs for Assertive Community Treatment ["PACT"] teams) will have different training needs. Customized focus groups and informal meeting sessions should supplement the needs assessment to determine the most critical training needs for each provider group, and for providers overall.

A key finding from the 2009 SDM summit was that SDM has never been incorporated into training for behavioral health providers. Similarly, pre-service training rarely contains content on involving clients in treatment decisions. SDM training should be interactive and should target the lowest-paid least-trained staff, which often have the most contact with consumers. The feasibility of incorporating SDM into medical education curricula should be given careful consideration. Once implemented, all training programs should be evaluated for effectiveness.

Finally, mental health providers, like consumers, should have access to decision support tools that are easy to use. To ensure that resources are used efficiently, efforts to develop decision support tools for providers should be coordinated to avoid duplication.

6. Formalize the Role of the Peer Specialist in Providing Decision Support

Peer support not only improves the well-being of people with mental illness, but it also enables mental health consumers to share information about different treatments. Through peer support groups, many consumers have obtained reliable and useful information about medications.

Additionally, “peer specialists” are mental health consumers who utilize their experience of mental health recovery to assist other consumers in articulating and reaching their personal recovery goals. More specifically, the peer specialist works with other consumers on problem solving, recovery/life goal setting, utilizing self-help recovery tools such as the Wellness Recovery Action Plan ("WRAP"), skill building, and establishing self-help groups. “Certified” peer specialists have gone through extensive training and passed an exam demonstrating their knowledge of key competencies.

In Massachusetts, certified peer specialists are offered and funded through a variety of different service delivery models, including PACT, day treatment programs, emergency service teams, and community-based flexible support teams. Not only does the peer specialist work to inspire clients, but also to guide and influence the perspectives of other treatment team members. Peer specialists also operate independently of treatment teams, as staff of the consumer-run Recovery Learning Communities.

Peers specialists are well-positioned to coach clients to actively participate in making treatment decisions with their providers. In this role, a peer specialist could train consumers to use decision support tools, provide direct assistance to consumers using decision supports, and coach consumers in preparing for a treatment meeting. Beyond certification, a continuing education course should be developed for peer specialists to learn to provide this specialized support.

7. Address Risk/Liability Concerns, and Propose Legislation

A model SDM system would provide clients and providers with access to correct, clear and concise information that is easily retrieved and updated, as well as the resources necessary to discuss relevant options without significantly draining provider resources. In addition, an SDM system must include legislation that eliminates the paternalistic physician-based and patient-based informed consent rules and replaces them with liability protection language that recognizes the priority of autonomy and the responsibilities of provider and client as a partnership of equals. Providers would no longer have to guess regarding their legal liability and they could improve the health outcomes of their patients by enabling them to be more invested in their treatment choice.[46] Summit participants strongly encouraged the adoption of public policies to address provider liability concerns. The major concern is that SDM will lead to more frequent negative outcomes because clients may choose to forgo treatments such as medications or elect to take on significant responsibilities of daily living, such as money management or employment.

In order to address these issues, the State of Washington passed a law in 2007 that recognizes SDM as an evidence-supported activity that is likely to produce improved medical outcomes through the use of decision aids and other decision supports. The law specifically contains liability protection language, with a signed "acknowledgement of shared decision making" document serving as prima facie of informed consent, reducing the potential liability for providers. For more information about Washington's law, see Appendix A and http://www.informedmedicaldecisions.org/pdfs/legislation.pdf. (Maine and Vermont are also working on bills that will encourage SDM in medicine.)

Ultimately, when a provider and client collaborate in the treatment decision, they are prioritizing patient autonomy over beneficence (provider taking action that serves the best interests of a client). In instances of disagreement after discussion, the client's preference should determine the treatment, since the client has to live with the decision and its implications. By protecting patient autonomy and acknowledging the importance of provider opinion and analysis, SDM provides the most effective method of enabling providers to satisfy their ethical obligations to clients. Stakeholders should explore all options to limiting liability for engaging in SDM.

8. Address Racial, Ethnic and Cultural Factors in SDM

Summit participants stated that a client's racial, ethnic and cultural background can affect his or her views about particular health conditions and treatments. In several cultures, there is deep stigma associated with seeking professional mental health services, and in particular the use of psychiatric medication.[47] Likewise, the extent to which clients desire involvement in treatment decisions, and the relative appeal of specific decision supports, are likely to differ by racial, ethnic and cultural groups.[48] Cultural attitudes on the following factors will likely affect a client's view on SDM:

- the role of family and friends in decision making
- the acceptable level of independence from the larger group
- the level of acceptance of the clinician as the "expert"

Every SDM initiative should take racial, ethnic and cultural identity and norms into account.

Endnotes

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